

COMMITTEE ON LEGISLATIVE RESEARCH  
OVERSIGHT DIVISION

**FISCAL NOTE**

L.R. No.: 2393-05  
Bill No.: Truly Agreed To and Finally Passed HCS for HB 948  
Subject: Children and Minors; Health Care; Health Care Professionals; Health Department  
Type: Original  
Date: May 16, 2007

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Bill Summary: This proposal modifies the requirements for the handling of newborn screening test.

**FISCAL SUMMARY**

<b>ESTIMATED NET EFFECT ON GENERAL REVENUE FUND</b>			
<b>FUND AFFECTED</b>	<b>FY 2008</b>	<b>FY 2009</b>	<b>FY 2010</b>
General Revenue	(\$57,646 to \$376,833)	(\$48,923 to \$465,766)	(\$50,190 to \$479,739)
<b>Total Estimated Net Effect on General Revenue Fund</b>	<b>(\$57,646 to \$376,833)</b>	<b>(\$48,923 to \$465,766)</b>	<b>(\$50,190 to \$479,739)</b>

<b>ESTIMATED NET EFFECT ON OTHER STATE FUNDS</b>			
<b>FUND AFFECTED</b>	<b>FY 2008</b>	<b>FY 2009</b>	<b>FY 2010</b>
Public Health Services Fund	\$0	Unknown	Unknown
<b>Total Estimated Net Effect on <u>Other</u> State Funds</b>	<b>\$0</b>	<b>Unknown</b>	<b>Unknown</b>

Numbers within parentheses: ( ) indicate costs or losses.  
This fiscal note contains 11 pages.

<b>ESTIMATED NET EFFECT ON FEDERAL FUNDS</b>			
FUND AFFECTED	FY 2008	FY 2009	FY 2010
<b>Total Estimated Net Effect on <u>All</u> Federal Funds</b>	<b>\$0</b>	<b>\$0</b>	<b>\$0</b>

<b>ESTIMATED NET EFFECT ON FULL TIME EQUIVALENT (FTE)</b>			
FUND AFFECTED	FY 2008	FY 2009	FY 2010
<b>Total Estimated Net Effect on FTE</b>	<b>0</b>	<b>0</b>	<b>0</b>

☐ Estimated Total Net Effect on All funds expected to exceed \$100,000 savings or (cost).

☒ Estimated Net Effect on General Revenue Fund expected to exceed \$100,000 (cost).

<b>ESTIMATED NET EFFECT ON LOCAL FUNDS</b>			
FUND AFFECTED	FY 2008	FY 2009	FY 2010
<b>Local Government</b>	<b>\$0</b>	<b>\$0</b>	<b>\$0</b>

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## FISCAL ANALYSIS

### ASSUMPTION

Officials from the **Department of Social Services** assume the proposal would have no fiscal impact on their agency.

In response to a similar proposal from this year (SB 80), officials from the **Missouri Consolidated Health Care Plan, Office of the State Courts Administrator, Department of Conservation, Department of Highways and Transportation** and the **Department of Insurance, Financial Institutions & Professional Registration** each assume the proposal would have no fiscal impact on their respective agencies.

Officials from the **Department of Health and Senior Services (DHSS)** state the following:

Section 191.317.2: States, "The specimen shall be retained for five years after initial submission to the Department. After five years, the specimen shall be destroyed."

The State Public Health Laboratory (SPHL) estimates that one 24 cu. ft. freezer will hold approximately 30,000 blood spots. At an average of 90,000 spots annually, three Ultralow minus 70 degrees Celsius freezers per year (15 over the five year period) will be required at an estimated cost of \$10,000 per freezer, or \$30,000 annually. Freezers would need to be replaced approximately every ten years.

In the first year, space requirements for three freezers, uninterruptible power supplies and processing of spots, would be adequately covered in the health laboratory. The storage space in the laboratory where these freezers would be kept is not electrically wired for this type of equipment. OA Facilities Maintenance estimates \$3,000 for an electrical contractor to run power to the storage area in year one. Since existing space is limited in the health lab, a leased facility that is a secure, temperature controlled warehouse with 220v electrical hookup and emergency power will be needed in subsequent years. This leased space will cost approximately \$7 to \$9 per square foot, or \$7,000-\$9,000 annually for 1,000 square feet of leased facility to house the program. To ensure electrical power to the freezers at all times, three uninterruptible power supply units will be purchased each year (1 per freezer) with an annual cost estimated at \$2,166 per unit.

ASSUMPTION (continued)

Section 191.317.2: States, "Unless otherwise directed under this section, a biological specimen may be released for purposes of anonymous scientific study. At the time of testing or up to five years after the specimen was initially submitted to the Department, the parent or legal guardian of the child from whom a biological specimen was obtained may direct the department to:

- (1) Return a biological specimen...after all screening tests have been performed;
- (2) Destroy a biological specimen in a scientifically acceptable manner after all screening tests required...have been performed; or
- (3) Store a biological specimen but not release the biological specimen for anonymous scientific study."

The SPHL will revise its newborn screening blood form to include consent of the parent or legal guardian to release the specimen for anonymous scientific study, or direct the Department to return, destroy, or store the specimen and not release it for study. Revision to the form will cost \$2,500 the first year.

The SPHL estimates that a half-time Senior Office Support Assistant will be needed to enter consent information into an information system, monitor categories of blood spot information for assignment to blood spot inventory, and recall blood spot information for shipping purposes.

Additionally, a half-time Medical Technologist Trainee/I/II will be needed to prepare specimens for storage of blood spots, monitor freezers daily for adequate storage conditions, process orders and prepare spots for shipping. Standard costs for FTE have been included for the two positions.

**Oversight** assumes the DHSS could absorb one-half Senior Office Support Assistant FTE and could absorb one-half Medical Technologist Trainee FTE.

DHSS assume this proposal would eliminate coverage to children under the age of six. DHSS currently has one child enrolled in the program within this age group who receives minimal services from the program. Minimal savings would be expected from eliminating this age group from services at this time.

**Cost estimate for children aged 6 through 18 years of age due to increased income eligibility guidelines:**

Estimates are based on the number of Missouri children aged 6 through 18 years who may have one of the disorders covered through the DHSS Metabolic Formula Program, require treatment with metabolic formula, and are not covered by Medicaid.

ASSUMPTION (continued)

This proposal will increase financial eligibility for this group from 185 percent of poverty to 300 percent of poverty. According to the 2006 Federal Poverty Level guidelines, the current poverty level for a family of four is \$20,000. Three hundred percent of the federal poverty level for a family of four is \$60,000. According to information in the 2000 Missouri Census, approximately 64% of Missouri households fall under the \$60,000 household income level.

Projected population: age 6 through 18 years of age = 1,026,960  
 Individuals age 6 through 18 years of age enrolled in any Medicaid program = (305,318)  
 Resulting population target group ages 6 through 18 years of age = 721,642

<b>Metabolic Diseases Covered by Expanded Newborn Screening</b>	<b>Incidence</b>	<b>Projected Population Size</b>	<b>Expected Number In This Population Base</b>
Phenylketonuria -PKU	1/15,000	721,642	48
Maple Syrup Urine Disease - MSUD	1/185,000 world wide 1/200 Mennonite population *	721,642	4
Homocystinuria	1/200,000	721,642	4
Citrullinemia	1/57,000	721,642	13
Argininosuccinic acidemia	1/250,000	721,642	3
Glutaric acidemia	1/40,000	721,642	18
Propionic acidemia	1/100,000	721,642	7
Methylmalonic acidemia	1/50,000	721,642	14
Isovaleric acidemia	1/230,000	721,642	3
3-hydroxy-3-methylglutaryl CoA lyase deficiency - HMG	unknown, rare	721,642	0
3-methylcrotonyl CoA carboxylase deficiency – 3MCC	unknown, rare	721,642	0
			<b>Total = 114</b>

\*Note: The Mennonite population was not included in the calculation for maple syrup urine disease as their numbers, based on religion, cannot be determined through Census data.

ASSUMPTION (continued)

Based on the above information, an estimated 73 children ( $114 \times 64\%$  poverty rate = 73) would be eligible for metabolic services at 300 percent of the federal poverty level. DHSS currently serves 2 children ages 6 through 18 in the Metabolic Formula Program. Of the remaining 71 (73-2) included in this group, DHSS assumes approximately 10% or 7 children would not be eligible to receive formula provided by Medicaid or MC+, and would therefore be eligible to receive services through the DHSS Metabolic Formula Program. With an annual cost of \$7,800 per person per year for formula, expanding eligibility to this age group would cost up to \$54,600 (7 children x \$7,800).

Considering the history of the program, the uncertainty of enrollment, the mix of third party payors, and the uncertainty of compliance (children taking formula regularly) it is difficult to determine how many of these new eligible children will actually enroll in the program, comply with the formula regimen, and incur a program expense. Therefore, DHSS estimates that program costs for this new group of eligibles will be between \$0 and \$54,600. The higher cost would be incurred if all estimated children would enroll and if they have no other means of payment for formula.

**Cost estimate for children aged 6 through 18 years of age with family incomes over 300% of poverty:**

Based on the above information, an estimated 41 children ( $114 \times 36\%$  = 41) with family incomes above the 300% of poverty rate would be eligible for metabolic services.

The Department is not an insurance agency and does not collect premiums. To address the bill's requirements of collecting premiums, the Department would institute cap amounts at each level of poverty from 300% to 400%, 401% to 500%, and above 500%. The maximum amount paid per child would be \$4,000, \$3,000 and \$2,000 respectively. This would, in effect, act as a requirement that the family participate in paying for their formula the same as if they were paying premiums. Total cost estimates for this group are based on the following assumptions:

- Number of children in age/income group = 41
- Number of children estimated at each income level not currently receiving benefits:
  1. 300% - 400% = 16 children less two already receiving services = 14 children
  2. 401% - 500% = 14 children (none currently receiving services) = 14 children
  3. Greater than 500% = 11 children (none currently receiving services) = 11 children

ASSUMPTION (continued)

- Estimated percent who will enroll in program (50% of all three income groups) =  $7 + 7 + 6$   
= 20 additional children
- Maximum cost per each income group:
  1. 300% - 400% =  $\$4,000 \times 7 = \$28,000$
  2. 401% - 500% =  $\$3,000 \times 7 = \$21,000$
  3. 500% and above =  $\$2,000 \times 6 = \underline{\$12,000}$Total =  $\$61,000$

Considering the history of the program, the uncertainty of enrollment, the mix of third party payors, and the uncertainty of compliance (children taking formula regularly, how many will participate given a cap on benefits), the Department is estimating a range of \$0 to \$61,000 for this group of eligibles.

**Cost estimate adults nineteen years and older due to increased income eligibility guidelines:**

Although eligibility for adults nineteen years of age and over will not change in this legislation, DHSS is assuming that increased publicity for the program will occur if this legislation is passed. The increased publicity may encourage a number of adults that meet income eligibility to enroll in the program.

Projected population: 19 years of age and older	= 4,288,197
Individuals 19 years and older enrolled in Medicaid program	= <u>(357,483)</u>
Resulting population target group ages 19 years and older	= 3,930,714

ASSUMPTION (continued)

<b>Metabolic Diseases Covered by Expanded Newborn Screening</b>	<b>Incidence</b>	<b>Projected Population Size</b>	<b>Expected Number In This Population Base</b>
Phenylketonuria -PKU	1/15,000	3,930,714	262
Maple Syrup Urine Disease - MSUD	1/185,000 world wide 1/200 Mennonite population	3,930,714	21
Homocystinuria	1/200,000	3,930,714	20
Citrullinemia	1/57,000	3,930,714	69
Argininosuccinic acidemia	1/250,000	3,930,714	16
Glutaric acidemia	1/40,000	3,930,714	98
Propionic acidemia	1/100,000	3,930,714	39
Methylmalonic acidemia	1/50,000	3,930,714	79
Isovaleric acidemia	1/230,000	3,930,714	17
3-hydroxy-3-methylglutaryl CoA lyase deficiency - HMG	unknown, rare	3,930,714	0
3-methylcrotonyl CoA carboxylase deficiency – 3MCC	unknown, rare	3,930,714	0
			<b>Total = 621</b>

\*Note: The Mennonite population was not included in the calculation for maple syrup urine disease as their numbers, based on religion, cannot be determined through Census data.

The federal poverty level under the present 2006 federal poverty level guidelines for a family of four equals \$20,000. Therefore 185% of the federal poverty level = \$37,000 or less (1.85 x \$20,000). According to information in the 2000 Missouri Census data, approximately 25% of Missouri households fall below 185% of the federal poverty level.

Based on the above information, an estimated 155 adults ( $621 \times 25\% = 155$ ) would be eligible for metabolic services at 185 percent of the federal poverty level. DHSS currently serves 27 adults ages 19 and over in the Metabolic Formula Program, leaving an estimated 128 additional adults eligible for the program. Although eligibility guidelines will not be changed for this group, DHSS believes that due to publicity resulting from the passage of the legislation, up to 10% of the additional eligible adults will enroll in the program ( $128 \times 10\% = 13$  new adults) if this legislation is passed and discussed in the healthcare community.



ASSUMPTION (continued)

With an estimated annual cost of \$10,200 per person per year for formula for this age group, DHSS estimates costs may increase up to \$132,600 (13 adults x \$10,200).

Considering the history of the program, the uncertainty of enrollment, the mix of third party payors, and the uncertainty of compliance (adults taking formula regularly), it is difficult to determine how many of these new eligible adults will actually enroll in the program, comply with the formula regimen, and incur a program expense. Therefore, DHSS estimates that program costs for this new group of eligibles will be between \$0 and \$132,600. The higher cost would be incurred if all estimated adults would enroll and if they have no other means of payment for formula.

The total cost for children and adults is estimated to be from \$0 to \$452,200 (\$0 to \$54,600 + \$0 to \$28,000 + \$0 to \$21,000 + \$0 to \$12,000 + \$0 to \$336,600).

<u>FISCAL IMPACT - State Government</u>	FY 2008 (10 Mo.)	FY 2009	FY 2010
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**GENERAL REVENUE FUND**

Costs - Department of Health and Senior Services

State Public Health Laboratory Costs	(\$57,646)	(\$48,923)	(\$50,190)
Child Metabolic Formula Costs	\$0 to (\$376,833)	\$0 to (\$465,766)	\$0 to (\$479,739)

**ESTIMATED NET EFFECT ON  
GENERAL REVENUE FUND**

<u>(\$57,646 to \$376,833)</u>	<u>(\$48,923 to \$465,766)</u>	<u>(\$50,190 to \$479,739)</u>
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**PUBLIC HEALTH SERVICES FUND**

Income - Department of Health and Senior Services

Fee	\$0	Unknown	Unknown
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**ESTIMATED NET EFFECT ON  
PUBLIC HEALTH SERVICES FUND**

<u>\$0</u>	<u>Unknown</u>	<u>Unknown</u>
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<u>FISCAL IMPACT - Local Government</u>	FY 2008 (10 Mo.)	FY 2009	FY 2010
	<u>\$0</u>	<u>\$0</u>	<u>\$0</u>

FISCAL IMPACT - Small Business

No direct fiscal impact to small businesses would be expected as a result of this proposal.

FISCAL DESCRIPTION

This legislation changes the laws regarding the handling of newborn screening test specimens. In its main provisions, the legislation requires specimens to be kept for five years after submission to the Department of Health and Senior Services and then destroyed unless otherwise directed by the parent or guardian.

This legislation specifies that a specimen released for anonymous study cannot contain information that identifies the donor.

This legislation specifies that the Department has authority over the use, retention, and disposal of specimens and the information collected in newborn screening tests.

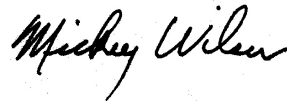
This legislation allows the Department to charge a fee for the use of newborn screening specimens for public health research.

This legislation modifies the Metabolic Formula Distribution Program. Under current law, formula for the treatment of inherited diseases of amino acids and organic acids are provided to persons meeting certain criteria and an income-based means test determined by the Department of Health and Senior Services. This legislation modifies those provisions to provide that in addition to the current program for applicants above the age of nineteen, the formula shall be available to an applicant between the ages of six to eighteen whose family income is below three hundred percent of the federal poverty level.

This legislation is not federally mandated, would not duplicate any other program and would not require additional capital improvements or rental space.

SOURCES OF INFORMATION

Department of Health and Senior Services  
Department of Social Services  
Missouri Consolidated Health Care Plan  
Office of the State Courts Administrator  
Department of Conservation  
Department of Highways and Transportation  
Department of Insurance, Financial Institutions & Professional Registration

A handwritten signature in black ink that reads "Mickey Wilson". The signature is written in a cursive, flowing style.

Mickey Wilson, CPA  
Director  
May 16, 2007